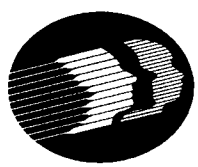
HIV and AIDS REPORTING IN DELAWARE

What you need to know!



DELAWARE HEALTH AND SOCIAL SERVICES
Division of Public Health
Center for Health Information and Disease Prevention
HIV/AIDS Epidemiology
Updated April 2007

FORWARD

This publication contains the procedure for the required reporting of HIV and AIDS cases to the Delaware Division of Public Health. It also provides answers to commonly asked questions and provides contact numbers for more information. HIV reporting provides supplementary data on HIV-infected Delawareans needed to enhance prevention efforts, improve resource allocation, and assist in evaluating public health interventions.

CONTENTS

APPENDICES

Current Delaware Regulations and Laws
Regarding HIV/AIDS Case Reporting

HIV/AIDS reporting is required under Delaware Code, Title 16, § 501 and § 502, and Delaware Regulations for the Control of Communicable and Other Disease Conditions, Chapter 42, para 7.4.1. It establishes the authority for Division of Public Health (DPH) to collect information on certain diseases, including HIV/AIDS patients. Reporting is required **regardless of their state of residence**; they must be reported if they are receiving care in Delaware.

Physicians, licensed health care professionals, and laboratory personnel who diagnose, suspect, or treat HIV are required to report cases to the DPH. When a patient is hospitalized, the hospital may file a report; however, **the ultimate responsibility to report is that of the attending physician.** Reports are to be made within 48 hours of diagnosis, suspicion or treatment.

How and Where to Report HIV/AIDS Cases

For your convenience, HIV/AIDS cases may be reported to DPH at 302-744-1015. Filing a report by telephone takes an average of five minutes. To expedite the reporting process, please have the patient's medical record available when you call.

If you prefer, you may complete a case report form and mail it to the address listed below. A copy of the Adult HIV/AIDS Confidential Case Report for patients 13 years of age or older at the time of diagnosis appears as **Appendix A**. The Pediatric HIV/AIDS Confidential Case Report for patients under the age of 13 is **Appendix B**. **You may copy these forms for your use in filing a case report**. By following these instructions, only authorized DPH staff will review the case report form.

Instructions:

Included with the HIV/AIDS Reporting in Delaware: *What you need to know!* packet, providers will receive envelopes to be used in a "double envelope" system. Please insert the completed case report form into the colorful envelope with security and confidentiality information on the outside. This colorful envelope should then be placed inside the postage paid envelope (also contained in packet), sealed and mailed to the Surveillance Coordinator.

To report an HIV or AIDS case, or for help with completing a case report form, contact the following authorized Division of Public Health staff:

Surveillance Officer: **302-744-1015**
Mailing Address: **HIV/AIDS Surveillance Office**
417 Federal Street
Dover, DE 19901

No Identified Risk (NIR) Case Investigation

The national HIV/AIDS surveillance program is coordinated by the Centers for Disease Control and Prevention (CDC). Standard information has been collected nationwide on documented cases of AIDS since 1984. In order to meet standard reporting requirements, DPH staff will investigate all cases reported without risk. This investigation will assist Delaware in developing an accurate database. CDC recognizes the following risk exposures:

- Men having sex with men since 1977 (MSM)
- Injecting drug use since 1977 (IDU)
- Received clotting factor for hemophilia or coagulation disorder
- Received transplant of tissue/organs or artificial insemination
- Transfusion of blood or blood components between 1978 through March 1985
- Heterosexual contact with a person who fits any of the above risk exposure groups
- Worked in a health care or clinical laboratory setting

NIR case investigations include contacting the reporting source of the case report. There are multiple sources of case reporting; primary care physicians, infection control personnel, case managers, review of medical records, autopsy reports, death certificates, and sexually transmitted disease/Ryan White registries. Should these methods fail to identify the client's risk exposure, authorized DPH personnel may also contact the client to request a confidential interview. NIR cases are considered open until a risk exposure is identified, the client is lost to follow up, or the client refuses to be interviewed. Closed cases may be reopened, however, with availability of new information.

Partner Notification

Regulations require physicians or health care professionals report the identity of patients' sexual or needle-sharing partner (s) to DPH so the partner may be notified of risk of infection, provided:

- the patient is diagnosed with HIV or AIDS; and
- the provider knows of a partner who could be at risk of infection; and
- the provider believes there is significant risk of harm to partner; and
- the provider believes partner does not suspect he or she is at risk; and
- the patient is unlikely to notify the partner; and
- the provider has made reasonable efforts to inform patient of the intended disclosure and to give patient opportunity to express preference of who will notify partner.

Questions and Answers

Q: What is reportable in Delaware?

A: Patients diagnosed with a positive HIV test or meeting the case definition of AIDS, ($CD4^+$ lymphocyte count <200 cells/μL or a $CD4^+$ <14% of total lymphocytes), all viral load test results, and all perinatal exposures to HIV are reportable. Appendix C gives the details of case definition.

Q: Why is it important to report HIV and AIDS?

A: Information from HIV and AIDS case reporting is used to monitor the HIV and AIDS epidemic in Delaware and the United States. HIV reporting allows the surveillance office to obtain information on HIV incidence and prevalence, identify emerging trends and patterns of HIV infection, and characterize the people most recently infected with HIV. Data are used to target prevention programs and allocate funds for treatment services. HRSA Title II funds under the Ryan White CARE Act are distributed to Delaware through a formula grant based on the number of HIV/AIDS cases reported.

Q: Who is required to report?

A: The following are required to report cases:

- Physicians or health care professionals who diagnose, suspect or treat HIV/AIDS
- Administrator of a health facility or state, county, or city prison in which there is a case of HIV/AIDS
- Person in charge of clinical or hospital laboratory, blood bank, mobile unit or other facility in which a laboratory examination yields positive evidence of HIV/AIDS
- All facilities obtaining blood from human donors for purposes of transfusion or manufacture of blood products shall report HIV

Q: What can I do to help?

A: You can help by gathering and submitting complete case report information, including risk exposure. Explain to your client that in the vast majority of AIDS cases, the virus (HIV) was acquired through identified transmission routes. **Review the different risk exposures with your client using the Risk Factor Assessment tool provided as appendix D. In addition, use the patient questionnaire to assist in risk ascertainment.** If your client is identifying an unusual transmission route for the virus, collect as much information as possible and share the information with an authorized DPH representative.

Q: What about anonymous testing? Is it still available to clients?

A: Anonymous counseling and testing remains available to all Delaware citizens. Test results from anonymous sites are reported to DPH, but names are not. For a list of current anonymous testing sites or to schedule an appointment, please contact the AIDS hotline at 1-800-422-0429.

Q: What happens to data once reported?

A: Once the case report is completed, it should be returned to DPH through previously described procedures (double envelope system, see page 2). Hard copies should **not** be made for the permanent medical record. You may wish to indicate on the medical record that the patient was reported to DPH (and the date of report). It is suggested that no record or case report form remain in the patient's medical chart.

Please do not assume a patient has been reported. DPH will sort through duplicate reports. Also, when a patient progresses from HIV positive to AIDS-defined, please inform DPH.

When DPH receives the case report form, it will be handled by authorized DPH personnel only. Information from the case report form will be entered into the secure HIV/AIDS Reporting System (HARS). On a monthly basis, demographic information from HARS will be sent to CDC via a secure system (names will NOT be sent). Only authorized DPH staff may access the secure database or HIV/AIDS Reporting System (HARS).

Q: What happens if I don't report?

A: There are penalties for not reporting patients as required by the regulations. Penalties are also assessed for confidentiality breaches. If the authorized Public Health staff receives a lab report on an HIV+ patient, the staff will check the database for patient's name. If, after a period of time, no case report is received, the authorized Public Health staff will contact the provider to request a complete case report and stress the importance of reporting within the established guidelines

Q: How is privacy protected?

A: The double envelope system directs the recipient to deliver the color distinctive inner envelope to a specific person within DPH. Only authorized personnel will open the brightly colored envelope. The HIV/AIDS Reporting System (HARS) stores all information on the case report form in specialized software developed by CDC. The disks containing HARS data are stored in locked cabinets located within a locked room. Only authorized DPH personnel have access to the secured cabinets. The computer where HARS resides is **not** connected to a network or the internet.

Q: What is a "name-based" system of reporting?

A: Each patient name, received by the authorized DPH representative, will be entered into the HARS secure database. All demographic information, to include the patient's name, will remain in the database. However, as stated previously, no names will be sent to CDC.

Q. What is the connection between Partner Notification and HIV Reporting?

A. Page two of the HIV/AIDS case report form contains the partner notification section. When the physician reports partners, only one person within DPH will review reports informing of the need for partner notification. The authorized DPH individual will complete a field record on the partner and provide it to a disease intervention specialist (DIS) within DPH. DIS professionals will make every effort to contact the partners and urge HIV testing.

I. STATE/LOCAL USE ONLY

Patient's Name: _____ Social Security #: _____ Phone No.: ( ) _____
(Last, First, M.I.)

Address: _____ City: _____ County: _____ State: _____ Zip Code: _____

RETURN TO STATE/LOCAL HEALTH DEPARTMENT — *– Patient identifier information is not transmitted to CDC! –*

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Disease Control and Prevention

ADULT HIV/AIDS CONFIDENTIAL CASE REPORT

(Patients ≥13 years of age at time of diagnosis)

II. HEALTH DEPARTMENT USE ONLY

Form Approved OMB No. 0920-0573 Exp Date 11/30/2005

DATE FORM COMPLETED: Mo. Day Yr. ☐☐ ☐☐ ☐☐

REPORT SOURCE: ☐☐

SOUNDEX CODE: ☐☐☐☐

REPORT STATUS: [1] New Report [2] Update

REPORTING HEALTH DEPARTMENT: State: _____ City/County: _____

State Patient No.: ☐☐☐☐☐☐☐☐☐☐

City/County Patient No.: ☐☐☐☐☐☐☐☐☐☐

III. DEMOGRAPHIC INFORMATION

DIAGNOSTIC STATUS AT REPORT (check one): [1] HIV Infection (not AIDS) [2] AIDS

AGE AT DIAGNOSIS: ☐☐ Years ☐☐ Years

DATE OF BIRTH: Mo. Day Yr. ☐☐ ☐☐ ☐☐

CURRENT STATUS: Alive [1] Dead [2] Unk. [9]

DATE OF DEATH: Mo. Day Yr. ☐☐ ☐☐ ☐☐

STATE/TERRITORY OF DEATH: _____

SEX: [1] Male [2] Female

ETHNICITY: (select one) [1] Hispanic [9] Unk [2] Not Hispanic or Latino

RACE: (select one or more) ☐ American Indian/Alaska Native ☐ Black or African American ☐ Asian ☐ Native Hawaiian or Other Pacific Islander ☐ White ☐ Unk

COUNTRY OF BIRTH: [1] U.S. [7] U.S. Dependencies and Possessions (including Puerto Rico) (specify): _____ [8] Other (specify): _____ [9] Unk

RESIDENCE AT DIAGNOSIS: City: _____ County: _____ State/Country: _____ Zip Code: ☐☐☐☐☐

IV. FACILITY OF DIAGNOSIS

Facility Name _____

City _____

State/Country _____

FACILITY SETTING (check one) [1] Public [2] Private [3] Federal [9] Unk.

FACILITY TYPE (check one) [01] Physician, HMO [31] Hospital, Inpatient [88] Other (specify): _____

This report to the Centers for Disease Control and Prevention (CDC) is authorized by law (Sections 304 and 306 of the Public Health Service Act, 42 USC 242b and 242k). Response in this case is voluntary for federal government purposes, but may be mandatory under state and local statutes. Your cooperation is necessary for the understanding and control of HIV/AIDS. Information in CDC's HIV/AIDS surveillance system that would permit identification of any individual on whom a record is maintained, is collected with a guarantee that it will be held in confidence, will be used only for the purposes stated in the assurance on file at the local health department, and will not otherwise be disclosed or released without the consent of the individual in accordance with Section 308(d) of the Public Health Service Act (42 USC 242m).

V. PATIENT HISTORY

AFTER 1977 AND PRECEDING THE FIRST POSITIVE HIV ANTIBODY TEST OR AIDS DIAGNOSIS, THIS PATIENT HAD (Respond to **ALL** Categories):

	Yes	No	Unk.
• Sex with male	[1]	[0]	[9]
• Sex with female	[1]	[0]	[9]
• Injected nonprescription drugs	[1]	[0]	[9]
• Received clotting factor for hemophilia/coagulation disorder	[1]	[0]	[9]
Specify disorder: [1] Factor VIII (Hemophilia A) [2] Factor IX (Hemophilia B) [8] Other (specify): _____			
• *HETEROSEXUAL* relations with any of the following:			
• Intravenous/injection drug user	[1]	[0]	[9]
• Bisexual male	[1]	[0]	[9]
• Person with hemophilia/coagulation disorder	[1]	[0]	[9]
• Transfusion recipient with documented HIV infection	[1]	[0]	[9]
• Transplant recipient with documented HIV infection	[1]	[0]	[9]
• Person with AIDS or documented HIV infection, risk not specified	[1]	[0]	[9]
• Received transfusion of blood/blood components (other than clotting factor)	[1]	[0]	[9]
First Mo. ☐☐ Yr. ☐☐ Last Mo. ☐☐ Yr. ☐☐			
• Received transplant of tissue/organs or artificial insemination	[1]	[0]	[9]
• Worked in a health-care or clinical laboratory setting	[1]	[0]	[9]
(specify occupation): _____			

Lab Name: _____ **VI. LABORATORY DATA** **Lab ID:** _____

1. HIV ANTIBODY TESTS AT DIAGNOSIS: (Indicate first test)

	Pos	Neg	Ind	Not Done	TEST DATE Mo.	Yr.
• HIV–1 EIA	[1]	[0]	–	[9]	☐☐	☐☐
• HIV–1/HIV–2 combination EIA	[1]	[0]	–	[9]	☐☐	☐☐
• HIV–1 Western blot/IFA	[1]	[0]	[8]	[9]	☐☐	☐☐
• Other HIV antibody test (specify): _____	[1]	[0]	[8]	[9]	☐☐	☐☐

2. POSITIVE HIV DETECTION TEST: (Record earliest test) Mo. ☐☐ Yr. ☐☐

☐ culture ☐ antigen ☐ PCR, DNA or RNA probe

• Other (specify): _____ Mo. ☐☐ Yr. ☐☐

3. DETECTABLE VIRAL LOAD TEST: (Record most recent test)

Test type* ☐☐ COPIES/ML ☐,☐☐☐,☐☐☐ Mo. ☐☐ Yr. ☐☐

*Type: 11. NASBA (Organon) 12. RT-PCR (Roche) 13. bDNA(Chiron) 18. Other

• Date of last documented negative HIV test (specify type): _____ Mo. ☐☐ Yr. ☐☐

• If HIV laboratory tests were not documented, is HIV diagnosis documented by a physician? [1] Yes [0] No [9] Unk.

If yes, provide date of documentation by physician ..... Mo. ☐☐ Yr. ☐☐

4. IMMUNOLOGIC LAB TESTS:

AT OR CLOSEST TO CURRENT DIAGNOSTIC STATUS

		Mo.	Yr.
• CD4 Count	☐,☐☐☐ cells/μL	☐☐	☐☐
• CD4 Percent	☐☐ %	☐☐	☐☐

First <200 μL or <14%

		Mo.	Yr.
• CD4 Count	☐,☐☐☐ cells/μL	☐☐	☐☐
• CD4 Percent	☐☐ %	☐☐	☐☐

VII. STATE/LOCAL USE ONLY

Physician's Name: _____ Phone No.: ( ) _____ Medical Record No. _____
(Last, First, M.I.)

Hospital/Facility: _____ Person Completing Form: _____ Phone No.: ( ) _____

– Patient identifier information is not transmitted to CDC! –

VIII. CLINICAL STATUS

CLINICAL RECORD REVIEWED: Yes [1] No [0]

ENTER DATE PATIENT WAS DIAGNOSED AS: Asymptomatic (including acute retroviral syndrome and persistent generalized lymphadenopathy): Mo. Yr. Symptomatic (not AIDS): Mo. Yr.

AIDS INDICATOR DISEASES	Initial Diagnosis Def.	Initial Diagnosis Pres.	Initial Date Mo.	Initial Date Yr.
Candidiasis, bronchi, trachea, or lungs	[1]	NA		
Candidiasis, esophageal	[1]	[2]		
Carcinoma, invasive cervical	[1]	NA		
Coccidioidomycosis, disseminated or extrapulmonary	[1]	NA		
Cryptococcosis, extrapulmonary	[1]	NA		
Cryptosporidiosis, chronic intestinal (>1 mo. duration)	[1]	NA		
Cytomegalovirus disease (other than in liver, spleen, or nodes)	[1]	NA		
Cytomegalovirus retinitis (with loss of vision)	[1]	[2]		
HIV encephalopathy	[1]	NA		
Herpes simplex: chronic ulcer(s) (>1 mo. duration); or bronchitis, pneumonitis or esophagitis	[1]	NA		
Histoplasmosis, disseminated or extrapulmonary	[1]	NA		
Isosporiasis, chronic intestinal (>1 mo. duration)	[1]	NA		
Kaposi's sarcoma	[1]	[2]		

AIDS INDICATOR DISEASES	Initial Diagnosis Def.	Initial Diagnosis Pres.	Initial Date Mo.	Initial Date Yr.
Lymphoma, Burkitt's (or equivalent term)	[1]	NA		
Lymphoma, immunoblastic (or equivalent term)	[1]	NA		
Lymphoma, primary in brain	[1]	NA		
Mycobacterium avium complex or *M.kansasii*, disseminated or extrapulmonary	[1]	[2]		
M. tuberculosis, pulmonary*	[1]	[2]		
M. tuberculosis, disseminated or extrapulmonary*	[1]	[2]		
Mycobacterium, of other species or unidentified species, disseminated or extrapulmonary	[1]	[2]		
Pneumocystis carinii pneumonia	[1]	[2]		
Pneumonia, recurrent, in 12 mo. period	[1]	[2]		
Progressive multifocal leukoencephalopathy	[1]	NA		
Salmonella septicemia, recurrent	[1]	NA		
Toxoplasmosis of brain	[1]	[2]		
Wasting syndrome due to HIV	[1]	NA		

Def. = definitive diagnosis Pres. = presumptive diagnosis

* RVCT CASE NO.: _____

- **If HIV tests were not positive or were not done, does this patient have an immunodeficiency that would disqualify him/her from the AIDS case definition?** [1] Yes [0] No [9] Unknown

IX. TREATMENT/SERVICES REFERRALS

Has this patient been informed of his/her HIV infection? [1] Yes [0] No [9] Unk.

This patient's partners will be notified about their HIV exposure and counseled by:
[1] Health department [2] Physician/provider [3] Patient [9] Unknown

This patient is receiving or has been referred for:

	Yes	No	NA	Unk.
• HIV related medical services	[1]	[0]	–	[9]
• Substance abuse treatment services	[1]	[0]	[8]	[9]

This patient received or is receiving:

	Yes	No	Unk.
• Anti-retroviral therapy	[1]	[0]	[9]
• PCP prophylaxis	[1]	[0]	[9]

This patient has been enrolled at:

Clinical Trial	Clinic
[1] NIH-sponsored	[1] HRSA-sponsored
[2] Other	[2] Other
[3] None	[3] None
[9] Unknown	[9] Unknown

This patient's medical treatment is primarily reimbursed by:
[1] Medicaid [2] Private insurance/HMO
[3] No coverage [4] Other Public Funding
[7] Clinical trial/ government program [9] Unknown

FOR WOMEN:
- This patient is receiving or has been referred for gynecological or obstetrical services: [1] Yes [0] No [9] Unknown
- Is this patient currently pregnant? [1] Yes [0] No [9] Unknown
- Has this patient delivered live-born infants? [1] Yes (if delivered after 1977, provide birth information below for the most recent birth) [0] No [9] Unknown

CHILD'S DATE OF BIRTH: Mo. Day Yr.

Hospital of Birth: _____
City: _____ State: _____

Child's Soundex:

Child's State Patient No.

X. COMMENTS: _____

Patient's Name: _____ Social Security No. _____

IX. MARITAL STATUS

Single	Married	Divorced	Separated	Widowed	Significant Other/Spouse
☐	☐	☐ ☐	☐	☐	

X. PARTNER NOTIFICATION

1. Does this patient have a partner or spouse that requires partner or spousal notification?
   ☐ No ☐ Yes (see below)
2. Are you confident that the patient will notify the partner or spouse?
   ☐ No ☐ Yes
3. Do you or does the patient want DPH to notify the partner or spouse?
   ☐ No ☐ Yes

Detailed information on partners or spouses is required for Partner Notification services. Please complete the following items for each partner. If there is additional information available, please attach a separate sheet outlining details.

Characteristic	Partner 1	Partner 2
Last, First Name, middle initial		
Alias name		
Address		
Phone		
DOB (age)		
Gender		
Race/Ethnicity		
Pregnancy status, if known		
Place of Employment		
Emergency or other important information		

Comments:_____

I. STATE/LOCAL USE ONLY

Patient's Name: _____ Phone No.: ( ) _____
(Last, First, M.I.)

Address: _____ City: _____ County: _____ State: _____ Zip Code: _____

RETURN TO STATE/LOCAL HEALTH DEPARTMENT — *– Patient identifier information is not transmitted to CDC! –*

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Disease Control and Prevention

PEDIATRIC HIV/AIDS CONFIDENTIAL CASE REPORT

(Patients <13 years of age at time of diagnosis)

CDC — Centers for Disease Control and Prevention

DATE FORM COMPLETED: Mo. Day Yr.

REPORT SOURCE:

II. HEALTH DEPARTMENT USE ONLY

Form Approved OMB No. 0920-0573 Exp Date 11/30/2005

SOUNDEX CODE:

REPORT STATUS: [1] New Report [2] Update

REPORTING HEALTH DEPARTMENT: State: _____ City/County: _____

State Patient No.:

City/County Patient No.:

III. DEMOGRAPHIC INFORMATION

DIAGNOSTIC STATUS AT REPORT: (check one) [3] Perinatally HIV Exposed [4] Confirmed HIV Infection (not AIDS) [5] AIDS [6] Seroreverter

DATE OF LAST MEDICAL EVALUATION: Mo. Yr.

DATE OF BIRTH: Mo. Day Yr.

AGE AT DIAGNOSIS: Years Months — HIV Infection (not AIDS) ... ; AIDS .....

CURRENT STATUS: [1] Alive [2] Dead [9] Unk.

DATE OF DEATH: Mo. Day Yr.

STATE/TERRITORY OF DEATH:

DATE OF INITIAL EVALUATION FOR HIV INFECTION: Mo. Yr.

Was reason for initial HIV evaluation due to clinical signs and symptoms? Yes [1] No [0] Unk. [9]

SEX: [1] Male [2] Female

ETHNICITY: (select one) [1] Hispanic [2] Not Hispanic or Latino [9] Unk.

RACE: (select one or more) [ ] American Indian/ Alaska Native [ ] Native Hawaiian or Other Pacific Islander [ ] Asian [ ] White [ ] Black or African American [ ] Unk

COUNTRY OF BIRTH: [1] U.S. [7] U.S. Dependencies and Possessions (including Puerto Rico) (specify): _____ [8] Other (specify): _____ [9] Unk.

RESIDENCE AT DIAGNOSIS: City: _____ County: _____ State/ Country: _____ Zip Code: _____

IV. FACILITY OF DIAGNOSIS

Facility Name: _____ City: _____ State/ Country: _____

FACILITY SETTING (check one) [1] Public [2] Private [3] Federal [9] Unk.

FACILITY TYPE (check one) [01] Physician, HMO [31] Hospital, Inpatient [88] Other (specify): _____

V. PATIENT/MATERNAL HISTORY *(Respond to ALL categories)*

- **Child's biologic mother's HIV Infection Status:** (check one)
  [1] Refused HIV testing [2] Known to be uninfected after this child's birth [9] HIV status unknown

  Diagnosed with HIV Infection/AIDS:
  [3] Before this child's pregnancy [5] At time of delivery [7] After the child's birth
  [4] During this child's pregnancy [6] Before child's birth, exact period unknown [8] HIV-infected, unknown when diagnosed

- **Date of mother's first positive HIV confirmatory test:** Mo. Yr.

- **Mother was counseled about HIV testing during this pregnancy, labor or delivery?** Yes [1] No [0] Unk. [9]

After 1977, this child's biologic mother had:

	Yes	No	Unk.
• Injected nonprescription drugs	1	0	9
• *HETEROSEXUAL* relations with:			
- Intravenous/injection drug user	1	0	9
- Bisexual male	1	0	9
- Male with hemophilia/coagulation disorder	1	0	9
- Transfusion recipient with documented HIV infection	1	0	9
- Transplant recipient with documented HIV infection	1	0	9
- Male with AIDS or documented HIV infection, risk not specified	1	0	9
• Received transfusion of blood/blood components (other than clotting factor)	1	0	9
• Received transplant of tissue/organs or artificial insemination	1	0	9

Before the diagnosis of HIV Infection/AIDS, this child had:

	Yes	No	Unk.
• Received clotting factor for hemophilia/coagulation disorder	1	0	9
(specify disorder): [1] Factor VIII (Hemophilia A) [2] Factor IX (Hemophilia B) [8] Other (specify): _____			
• Received transfusion of blood/blood components (other than clotting factor)	1	0	9
First: Mo. Yr. Last: Mo. Yr.			
• Received transplant of tissue/organs	1	0	9
• Sexual contact with a male	1	0	9
• Sexual contact with a female	1	0	9
• Injected nonprescription drugs	1	0	9
• Other (Alert State/City NIR Coordinator)	1	0	9

VI. STATE/LOCAL USE ONLY

Physician's Name: _____ Phone No.: ( ) _____ Medical Record No. _____
(Last, First, M.I.)

Hospital/Facility: _____ Person Completing Form: _____ Phone No.: ( ) _____

– Physician identifier information is not transmitted to CDC! –

VII. LABORATORY DATA

1. HIV ANTIBODY TESTS AT DIAGNOSIS: (Record all tests, include earliest positive)

	Positive	Negative	Indeterminate	Not Done	TEST DATE Mo.	TEST DATE Yr.
• HIV-1 EIA	1	0	–	9		
• HIV-1 EIA	1	0	–	9		
• HIV-1/HIV-2 combination EIA	1	0	–	9		
• HIV-1/HIV-2 combination EIA	1	0	–	9		
• HIV-1 Western blot/IFA	1	0	8	9		
• HIV-1 Western blot/IFA	1	0	8	9		
• Other HIV antibody test (specify): _____	1	0	8	9		

2. HIV DETECTION TESTS:
(Record all tests, include earliest positive)

	Positive	Negative	Not Done	TEST DATE Mo.	TEST DATE Yr.
• HIV culture	1	0	9		
• HIV culture	1	0	9		
• HIV antigen test	1	0	9		
• HIV antigen test	1	0	9		
• HIV DNA PCR	1	0	9		
• HIV DNA PCR	1	0	9		
• HIV RNA PCR	1	0	9		
• HIV RNA PCR	1	0	9		
• Other, specify _____	1	0	9		

3. HIV VIRAL LOAD TEST: (Record all tests, include earliest detectable)

*Type: 11. NASBA (Organon) 12. RT-PCR (Roche) 13. bDNA(Chiron) 18. Other

Test type*	Detectable Yes	Detectable No	Copies/ml	Test Date Mo.	Test Date Yr.
	1	0			
	1	0			

4. IMMUNOLOGIC LAB TESTS: (At or closest to current diagnostic status)

		Mo.	Yr.
• CD4 Count	cells/μL		
• CD4 Count	cells/μL		
• CD4 Percent	%		
• CD4 Percent	%		

5. If HIV tests were not positive or were not done, or the patient is less than 18 months of age, does this patient have an immunodeficiency that would disqualify him/her from the AIDS case definition? ..... Yes 1 No 0 Unk. 9

6. If laboratory tests were not documented, is patient confirmed by a physician as:

	Yes	No	Unk.	Date of Documentation Mo.	Date of Documentation Yr.
• HIV-infected	1	0	9		
• Not HIV-infected	1	0	9		

VIII. CLINICAL STATUS

AIDS INDICATOR DISEASES	Initial Diagnosis Def.	Initial Diagnosis Pres.	Initial Date Mo.	Initial Date Yr.
Bacterial infections, multiple or recurrent (including Salmonella septicemia)	1	NA		
Candidiasis, bronchi, trachea, or lungs	1	NA		
Candidiasis, esophageal	1	2		
Coccidioidomycosis, disseminated or extrapulmonary	1	NA		
Cryptococcosis, extrapulmonary	1	NA		
Cryptosporidiosis, chronic intestinal (>1 mo. duration)	1	NA		
Cytomegalovirus disease (other than in liver, spleen, or nodes) onset at >1 mo. of age	1	NA		
Cytomegalovirus retinitis (with loss of vision)	1	2		
HIV encephalopathy	1	NA		
Herpes simplex: chronic ulcer(s) (>1 mo. duration); or bronchitis, pneumonitis or esophagitis, onset at >1 mo. of age	1	NA		
Histoplasmosis, disseminated or extrapulmonary	1	NA		
Isosporiasis, chronic intestinal (>1 mo. duration)	1	NA		
Kaposi's sarcoma	1	2		
Lymphoid interstitial pneumonia and/or pulmonary lymphoid hyperplasia	1	2		
Lymphoma, Burkitt's (or equivalent term)	1	NA		
Lymphoma, immunoblastic (or equivalent term)	1	NA		
Lymphoma, primary in brain	1	NA		
Mycobacterium avium complex or *M.kansasii*, disseminated or extrapulmonary	1	2		
M. tuberculosis, disseminated or extrapulmonary*	1	2		
Mycobacterium, of other species or unidentified species, disseminated or extrapulmonary	1	2		
Pneumocystis carinii pneumonia	1	2		
Progressive multifocal leukoencephalopathy	1	NA		
Toxoplasmosis of brain, onset at >1 mo. of age	1	2		
Wasting syndrome due to HIV	1	NA		

Def. = definitive diagnosis Pres. = presumptive diagnosis

Has this child been diagnosed with pulmonary tuberculosis?* 1 Yes 0 No 9 Unk. If yes, initial diagnosis and date: 1 Definitive 2 Presumptive Mo. Yr. *RVCT CASE NO.:

IX. BIRTH HISTORY (for PERINATAL cases only)

Birth history was available for this child: [1] Yes [0] No [9] Unk. ***If No or Unknown, proceed to Section X.***

HOSPITAL AT BIRTH:

Hospital:_____ City:_____ State:_____ Country:_____

RESIDENCE AT BIRTH:

City:_____ County:_____ State/ Country:_____ Zip Code:_____

BIRTHWEIGHT: (enter lbs/oz OR grams)

____ lbs. ____ oz

____ grams

BIRTH: **Type:** .... [1] Single [2] Twin [3] >2 [9] Unk.

Delivery: ..... [1] Vaginal [2] Elective Caesarean [3] Non-elective Caesarean [4] Caesarean, unk. type [9] Unk.

Birth Defects: .... [1] Yes [0] No [9] Unk.

Specify type(s):_____ **Code:** ____.____

NEONATAL STATUS:

[1] Full term

[2] Premature

Weeks ____ 99 = Unk.

PRENATAL CARE:

Month of pregnancy prenatal care began: ____ mos. 99 = Unk. 00 = None

Total number of prenatal care visits: ____ 99 = Unk. 00 = None

- **Did mother receive zidovudine (ZDV, AZT) during pregnancy?** Refused [8] Yes [1] No [0] Unk. [9]
- **Did mother receive zidovudine (ZDV, AZT) during labor/delivery?** Refused [8] Yes [1] No [0] Unk. [9]
- **If yes, what week of pregnancy was zidovudine (ZDV, AZT) started?** Weeks: ____ 99 = Unk.
- **Did mother receive zidovudine (ZDV, AZT) prior to this pregnancy?** Yes [1] No [0] Unk. [9]
- **Did mother receive any other Anti-retroviral medication during pregnancy?** Yes [1] No [0] Unk. [9]
  If yes, specify:_____
- **Did mother receive any other Anti-retroviral medication during labor/delivery?** Yes [1] No [0] Unk. [9]
  If yes, specify:_____

Maternal Date of Birth Mo. Day Yr. ____

Maternal Soundex: ____ _____

Maternal State Patient No. _____

Birthplace of Biologic Mother:

[1] U.S. [7] U.S. Dependencies and Possessions (including Puerto Rico) (specify):_____

[8] Other (specify):_____ [9] Unk.

X. TREATMENT/SERVICES REFERRALS

This child received or is receiving:

	Yes	No	Unk.	DATE STARTED Mo.	Day	Yr.
• Neonatal zidovudine (ZDV, AZT) for HIV *prevention*	[1]	[0]	[9]			
• Other neonatal anti-retroviral medication for HIV *prevention*	[1]	[0]	[9]			
• Anti-retroviral therapy for HIV *treatment*	[1]	[0]	[9]			
• PCP prophylaxis	[1]	[0]	[9]			

If yes, specify:_____

Was child breastfed? Yes [1] No [0] Unk. [9]

This child has been enrolled at:

Clinical Trial: [1] NIH-sponsored [2] Other [3] None [9] Unk.

Clinic: [1] HRSA-sponsored [2] Other [3] None [9] Unk.

This child's medical treatment is primarily reimbursed by:

[1] Medicaid [2] Private insurance/HMO [3] No coverage [4] Other Public Funding [7] Clinical trial/government program [9] Unk.

This child's primary caretaker is:

[1] Biologic parent(s) [2] Other relative [3] Foster/Adoptive parent, relative [4] Foster/Adoptive parent, unrelated [7] Social service agency [8] Other (specify in Section XI.) [9] Unk.

XI. COMMENTS:

(XI. COMMENTS CONTINUED ON THE BACK)

XI. COMMENTS (continued)

Appendix C

What is the AIDS Case Definition?

An adult or adolescent (13 years or older) with documented human immunodeficiency virus (HIV) infection confirmed by a Western blot or other confirmatory test and who has one or more of the following conditions:

(♦= Added in 1993 expansion of the AIDS surveillance case definition)

- $CD4^+$ lymphocyte count <200 cells/μL or a $CD4^+$ <14% of total lymphocytes ♦
- Candidiasis of bronchi, trachea, or lungs
- Candidiasis, esophageal
- Cervical cancer, invasive ♦
- Coccidioidomycosis, disseminated and extrapulmonary
- Cryptococcosis, extrapulmonary
- Cryptosporidiosis, chronic intestinal (> 1 month duration)
- Cytomegalovirus disease (other than liver, spleen, or nodes)
- Cytomegalovirus retinitis (with loss of vision)
- HIV encephalopathy
- Herpes simplex: chronic ulcer(s) (> 1 month duration); or bronchitis, pneumonitis, or esophagitis
- Histoplasmosis, disseminated or extrapulmonary
- Isosporiasis, chronic intestinal (> 1 month duration)
- Kaposi's sarcoma
- Lymphoma, Burkitt's (or equivalent term)
- Lymphoma, immunoblastic (or equivalent term)
- *Mycobacterium avium* complex or *M. kansasii*, disseminated or extrapulmonary
- *Mycobacterium tuberculosis*, any site (pulmonary ♦) or extrapulmonary
- *Mycobacterium*, other species or unidentified species, disseminated or extrapulmonary
- *Pneumocystis carinii* pneumonia
- Pneumonia, recurrent (2 or more episodes in a 12-month period) ♦
- Progressive multifocal leukoencephalopathy
- Toxoplasmosis of the brain
- Wasting syndrome due to HIV

The Pediatric AIDS Case Definition

Children under 13 years of age with documented human immunodeficiency virus (HIV) infection confirmed by a Western blot or other confirmatory test that have one or more of the conditions defining an adult/adolescent case but excepting the first and fourth conditions on appendix C.

Additional conditions that may define a pediatric case are:

- Bacterial infections, multiple or recurrent (including Salmonella septicemia)
- Lymphoid interstitial pneumonia and/or recurrent lymphoid hyperplasia

Appendix D

TALKING WITH YOUR PATIENTS ABOUT BEHAVIORAL RISK FACTORS FOR HIV AND AIDS

Patients may be uncomfortable disclosing personal risk factors and hesitant to respond to questions about sensitive issues such as sexual behaviors and illicit drug use. However, evidence suggests that when asked, patients will often discuss behaviors that increase their risk of acquiring HIV. Evidence also suggests that some patients have greater confidence in their clinician's ability to provide high-quality care when asked about sexual history during the initial visits. Of course, the more comfortable you are discussing these issues, the more comfortable your patients will be.

Here are some ideas for talking with your patients.

PUT YOUR PATIENT AT EASE

- Reassure them their responses will remain confidential.
- Let them know that you ask all your patients these types of questions.
- Tell them that the information they provide about their sexual and drug use behaviors will help you provide the best possible care.
- Respect a patient's choice not to answer a question. Showing them respect increases the chance they will provide the information later.

HONEST RESPONSES ARE MORE LIKELY IF THE QUESTION IS WORDED TO "NORMALIZE" THE BEHAVIOR

- "Some people inject drugs. Have you ever done that?"
- "Some people have had anal intercourse. Have you ever done that?"
- "Some people exchange sex for drugs or money. Have you ever done that?"

LABELS CAN BE MISLEADING

- Some men do not consider themselves "gay" if they practice same sex anal insertive intercourse, but their receptive partners may be considered to be "gay".
- The question, "Are you a homosexual?" may be answered with "no" by a person who has had only a few same sex encounters or considers him/herself to be bisexual.
- Describe behaviors instead of assigning labels to the behavior. Use terms like "drug user", "men who have sex with men", "women who have sex with women", "sex worker"

AT THE END OF THE SESSION

- Summarize the patients responses to make sure you both understand what was said
- Encourage the patient to ask questions about any issues he or she did not understand

Source:
Gerbert B, Bronstone A, Pantilat S, et al. When asked, patients tell: disclosure of sensitive health-risk behaviors. Med Care 1999;37:104-11 MountainPlains AIDS Education and Training Center

PATIENT QUESTIONNAIRE

In order to understand your risk factors for HIV, we have to ask you some very personal questions. You may be embarrassed but your answers are very important. Knowing your risk factors for HIV may help keep you and others you care about healthier. We encourage you to talk to the medical staff about your concerns and ask any questions you may have. All information is kept strictly confidential.

THE QUESTIONS IN THIS SECTION ARE ABOUT YOU BEFORE YOU FOUND OUT YOU WERE HIV POSITIVE

1. Did you have sex with a male?
2. Did you have sex with a female?
3. Did you use needles to inject heroin, cocaine, steroids or any other drug that was not prescribed by a doctor?
4. The following are currently unlikely ways to get HIV. We would like to know if you have had any of the following happen to you since February, 1985. *Please check all that apply:*

   ____ transfusion of blood or blood products ____ hemophilia or other bleeding disorder

   ____ organ/tissue transplant ____ artificial insemination

5. Did you work in a health care or laboratory setting where you might have been exposed to human blood or other body fluids? If yes, please state your occupation_____
6. How do you think you got infected with HIV? _____

ANSWER THE QUESTIONS IN THIS SECTION IF YOU HAD A SEX PARTNER OF THE OPPOSITE SEX BEFORE YOU FOUND OUT YOU WERE HIV POSITIVE

7. Women only: Before you found out you were HIV positive, did any of your male sex partners have sex with other men?
8. Before you found out you were HIV positive, did any of your opposite sex partners use needles to inject heroin, cocaine, steroids, or any other drug that was not prescribed by a doctor?
9. Before you found out you were HIV positive, did any of your sex partners receive a transfusion of blood/blood products or organ/tissue transplant before they found out they had HIV or AIDS?
10. Before you found out you were HIV positive, did any of your opposite sex partners have hemophilia or any other bleeding disorder?
11. Before you found out you were HIV positive, did any of your opposite sex partners have HIV or AIDS?
12. Before you found out you were HIV positive, were any of your opposite sex partners born outside of the United States? If yes, where_____
13. Before you found out you were HIV positive, did any of your opposite sex partners live or work outside the U.S.? If yes, where_____
14. Before you found out you were HIV positive, did you have a Sexually Transmitted Disease (STD)?
15. Before you found out you were HIV positive, did you trade money, drugs, or gifts for sex?
16. Before you found out you were HIV positive, did you use crack, cocaine, or crystal meth?
17. Did you have more than one sex partner in the year before you found out you were HIV positive?